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A Review of the Impact of an Integrated Health And Social Care System On People With Dementia

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Abstract:

As England's demographic changes with an increasing ageing population so does the burden of long-term diseases such as dementia. Our current care system is no longer appropriate to deal with these changes. An integrated system, which can provide streamline care for both the health and social care needs is required. It is widely acknowledged that an integrated system can bring a number of advantages, which can be fundamental to its success. For that reason the Government have introduced a number of policies and related documents over the past two decades on developing an integrated health and social care service. However, a strong evidence-base demonstrating the positive impacts of an integrated care system is lacking, particularly in the case for older people with dementia.

Aim: To evaluate the impact of integrated health and social care policy and its related documents on people with dementia.

Objectives: To gain an understanding of integrated care policies, their related documents and their recorded impact on people with dementia.

Method: Systematic literature review.

Findings: There is little, if any evidence on the impact of integrated care on people with dementia.

Keywords:

Integrated care, policy, dementia

Introduction

England's population is changing, more and more, people are living to an older age, which has led to a rise in the number of people with dementia. Built upon the same need as 70 years ago, to meet the encumbrance of accidents, emergencies and diseases such as cancer, our current care system is no longer appropriate (Ham et al, 2011). People, specifically those with multiple care needs due to a chronic, long-term disease such as dementia, are being failed by a fragmented care system provided by the National Health System (NHS) and Local Authority (LA) in England. Issues include (DoH, 2013):

- "People having to re-tell their story every time they encounter a new service;
- People not getting the support they need because different parts of the system don't talk to each other or share appropriate information and notes;

- Older people discharged from hospital to homes not adapted to their needs, only to deteriorate or fall and end up back in A&E;
- Home visits from different health or care workers at different times, with no effort to fit in with people's requirements; and
- Patients' facing long waits in hospital before being discharged. Delayed discharges cost the NHS £370 million a year".

It is widely assumed that an integrated care system would address the problems that the current system has, and generate a number of advantages, which would be fundamental to its success (Humphries & Gregory, 2010, Lewis et al, 2010; Curry & Ham, 2010, Humphries and Curry, 2011). These advantages include, amongst others (Humphries & Gregory, 2010 and Humphries and Curry, 2011, pp.2.):

- "Better outcomes for people, e.g., living independently at home with maximum choice and control;
- Emphasis upon the prevention of illness and self care;
- More efficient use of existing resources by avoiding duplication and ensuring people receive the right care, in the right place, at the right time;
- Improved access to health and social care services;
- Improved experience of care services;
- Improved user satisfaction of care services; and
- A decrease in the overall expenditure."

For the above reasons the Government, academics and practitioners continue to develop policies, tools and strategies to support and/or maintain an integrated health and social care service delivery (e.g. Integrated Care Networks (ICN), Partnership for Older People Project (POPP) and "Sally Ford" of Salford. All of which take time and money to develop and maintain.

However, a strong evidence-base demonstrating positive impacts of integrated care systems is lacking (Ramsay and Fulop, 2008; Smith, E. et al., 2009; Curry and Ham 2010; Rosen et al., 2011). Moreover, as pointed out by Ramsay and Fulop (2008) most research into health and social care integration focuses upon "process measures" such as waiting times, admissions to hospital, or service responsiveness rather than "outcome measures" of the benefits to service users. In this regard, the impacts related to integrated care are assumed and not the result of substantiation evidence. (Armitage et al., 2009).

The purpose of this paper is to present the findings of a review into the impact of integrated health and social care governmental policies on people with dementia. This will be undertaken through a synthesis of policy based and impact literature.

Dementia disease – facts and figures

“Dementia is one of the most important issues we face as the population ages” (DoH, 2011). There are approximately 750,000 people in the UK living with dementia (DoH, 2011; APPG, 2011), just under half of these, have been diagnosed (APPG, 2011). “The number of people with Alzheimer's disease, dementia and senility is projected to increase by over 70% in England between 2010 and 2030” (Verne et al., 2011).

In this article dementia is considered as a condition, it is the result of brain damage from different diseases and conditions that cause a loss of brain function. It is, generally, a progressive disease whose symptoms ultimately become severe leading to death. The disease usually attacks the brain functions that can result in memory loss, mood changes problems with communication and reasoning and a decrease in the ability and skill in carrying out daily activities e.g. washing, dressing, cooking and caring for self (Alzheimer's Society, 2011; Dementia UK, 2011).

Several types of dementia exist, most common type being Alzheimer's disease, with it being responsible for 62% of all dementia cases. Alzheimer's causes the cells of the brain to die quicker than those in a healthy brain (Dementia UK), which leads it to be the greatest cause of 'progressive intellectual deficit in older people' (Wells, 1978 in Hughes et al., 1982, p. 566). The majority of people affected by dementia are older people. Over 95% of those who have dementia is aged 65 years or over (Victor, 2010).

Integrated Care

The concept of 'integrated care' can be understood in different ways. Through a concept analysis into the term 'integrated care', it is clear that much ambiguity exists and that the term is used interchangeably with the words 'partnership', 'inter-agency', 'collaboration', 'joint working', 'coordination of care' and 'continuity of care'. The shared fundamentals associated with it and its related terms are:

- Integration is a type of process/set of processes (e.g. Real, Virtual, Vertical, Horizontal) of joint working between individuals and organisations at different levels (e.g. Macro, Meso, Micro). (Pruitt et al., 2002; Kings Fund, 2011; Valentijn, et al., 2013).
- Integration is implemented to deliver improved outcomes to service users (Curry and Ham, 2010).

These two views represent the duality related to definition of 'integrated care', i.e. the former considers it as a 'process', whilst the later focus on the outcomes it generates. Thus, for the purpose of this article, integrated care means:

“Working together across boundaries to deliver a successful and streamlined service to the end-user”. It is about putting the patient at the centre of care delivery through a coherent process/set of processes between organisations/people/services that enable greater transparency between partners as well as enhanced benefits for service users. Informing the process are a number of foundational tools and progressive approaches: creating an operational definition, shared values, goals and knowledge (Suter, et al., 2009).

Integrated care can be described as occurring across a continuum (Kodner and Spreeuwenberg, 2002) from co-operation between separate organisations, to multi-disciplinary networks coordinating care, to pooled funding, joint planning, management, and multi-disciplinary teams. Integration of care can happen at any point of the patient's journey from assessment to referral through to diagnosis, treatment and discharge. For that reason, a wide classification of integrated care according to a number of different types and levels exists that helps with defining the term. The different types include: real and virtual, vertical and horizontal, organizational and care coordination, full structural, integrated networks and hybrid. Whilst the levels are three tiers: Macro level, Meso level and Micro level (Pruitt et al., 2002, Kings Fund 2011, Valentijn, et al., 2013). These are presented below.

Real and Virtual Integration: Real integration is the formal merging of services or organisations, with paper work such as contracts to declare this (Kings Fund, 2011). Real integration would involve an official agreement at the senior management for a full structural joining of two or more service organisations. The result would be that all those working within the different service organisations would belong to the same group. Official procedures, finances, human resources become shared by the newly created service organisation. Virtual integration, is less formal, it is the unofficial work between providers through partnerships, networks and alliances (Kings Fund, 2011). Virtual integration refers to the organisation of groups who share a goal but do not have mutual ownership. The level of virtual integration can differ and it can involve official governance contracts or be built on loose alliances (Curry and Ham, 2010)

Vertical and Horizontal Integration: Vertical integration refers to integrating care across distinctive levels within a same service organisation. For instance, integration between social, primary and secondary care at different stages of the care economy or integration along the care pathways and supply chain (Ramsay, A., Fulop, N. and Edwards, N. 2009, Rumbold, B. and Shaw, S.E. 2010, Shaw et al, 2011). Distinctively, horizontal integration refers to the collaboration of care providers, for instance, care delivered by a multi-disciplinary team such as grouping outpatient clinics within a geographic network of providers (Ramsay, Fulop and Edwards, 2009; Rumbold and Shaw, 2010; Shaw et al 2011).

Macro, Meso and Micro Levels: this classification refers to the scale of integration. Macro level is the top level of integration at policy level where service providers seek to deliver integrated care across all available services to the whole population; Meso level is the middle level, i.e. *healthcare organisation and community* level and it refers to service providers aim to deliver integrated care to a particular group of people that have the same health issue, it is disease orientated (e.g. NHS); Micro level refers to, *patient interaction*. Through care approaches such as coordination and care planning the service providers deliver integrated care to service users (e.g. Doctors). (Pruitt et al., 2002; Kings Fund, 2011; Valentijn, et al., 2013). Each level should be considered when delivering a fully effective and efficient integrated system, as each interacts and influences the others. However there are systems, which focus on only one or two of the levels.

Research Method

There are several challenges in designing a research method for the aim of this article. Ideally, finding identical cases of standardised integration where to collect information would provide relevant insights on its impact. Alternatively, a case study would also generate the sought evidence of impact. However, there are known issues related to the lack of standardised approaches when it comes to implementing integration that create barriers to the collection of reliable evidence. There are also issues around the extent that integration is realised or not, i.e. the difference between how integration occurs and how it is perceived to occur. Finally, there are epistemological difficulties of establishing a cause-effect relationship between integration and outcomes and different measures of impact have different realisation spans.

Considering the issues raised above, a systematic literature review was chosen as the appropriated method for evidence gathering and the formation of a critical viewpoint regarding the problem investigated as well as the research approaches being used in this field. Systematic reviews differ from traditional narrative reviews by adopting a replicable, scientific and transparent process which aims to minimize bias through exhaustive and time-consuming literature searches of published and unpublished studies and by providing an audit trail of the reviewer's decisions, procedures and conclusions (Cook et al., 1997; Tranfield et al., 2003). Findings from this process will feed into the development of a conceptual framework and the next stages of research that will be focused on gathering primary evidence. A conceptual framework is a way to focus and bring together the information and data obtained from the literature review. The framework also highlights the main areas to be researched. The conceptual framework is the 'researchers map of the territory being investigated... as the explorer's knowledge of the terrain improves the map becomes correspondingly more differentiated and integrated' (Miles and Huberman, 1994, p.32-33). The conceptual framework developed for this article corroborated the gap in impact studies of integrated care for people with dementia and therefore justifies the need for research in this area.

As discussed by Codinhoto et al., (2009), despite the benefits of this approach, not all steps of a systematic search can be applied to social sciences research. Therefore, the resulting process for the extensive review included academic and political articles on the impact of integrated health and social dementia care policies only. This review is encompassing of articles from a range of domains including management, service and healthcare. Details about each step taken as part of the systematic review are presented below.

1. To *identify policies* related to the integration of health and social care. Through a literature search using appropriate key words. The keywords were derived from the different terms used interchangeably with integration as identified through the concept analysis in integration. They are: partnership, inter-agency, collaboration, coordination of care, continuity of care and joint working, these were used along with the words integration, health care and social care. No Boolean operators were used. The databases used for these key word searches were: Department of Health, www.parliament.co.uk. The searches took place between July and January 2012. Only policy related documents were required from this search and so an inclusion and exclusion

criteria had to be used. Any documents other than policy for example papers, reviews or notes were excluded and all policy related documents such as Bills, Acts, Strategies, white papers, green papers were included. There was no date restriction on this search.

2. To *highlight* and provide details of those related to *dementia care*. This involved reviewing the identified policies and identifying if dementia was on the agenda. This began in January 2012 and lasted one month. Content identification was done using 'word search' tool. The terms 'dementia' and 'alzheimers' were used to identify relevant documents.
3. To *collect evidence* of the *impact* of these policies through a review of impact studies. This was achieved through review of literature. The keywords used were the titles of the policies (e.g. The New NHS: Modern and Dependable) plus the words audit, review, impact and evaluation. Boolean operators were used if they were within the title of the policy. Google Scholar, NHS Evidence, The Policy Press and Social Care Online. These searches began in December 2011 and ended in April 2012. For this step the inclusion and exclusion criteria was based upon the reading of identified abstract/synopsis to make an informed decision as to whether the document was a review of a specific policy.
4. To *raise awareness* regarding the *methods* used in the impact studies. This was done by ensuring only those peer reviewed were included, as it was assumed that the method is valid if it has been through this process.

Steps 1 to 4 of the systematic research process were concluded in 2013 and the conceptual framework was developed. This allowed the researcher to gain a thorough understanding of the impact of integrated health and social dementia care related policies on people with dementia. The review and process also provided an overview of the elements that are required to develop an integrated health and social care system for people with dementia. These findings will be presented in the next section.

Findings

Through undertaking the systematic review and developing the conceptual framework detailing policy and its related documents concerning integrated dementia care and the impact they had, the following issues were highlighted:

Facts and figures:

The review revealed that, from the 1980s to 2011, 32 policies (and related documents) linked to integrated care were published; 17 out of those were specifically linked to dementia care and integration, 4 of the 32 documents were related to integrated care for older people with complex needs but not specifically dementia. Out of the 17 relevant policies 15 recorded little or no evidence of impact.

The below timeline provides an overview of when the 17 relevant policies and related documents were published.

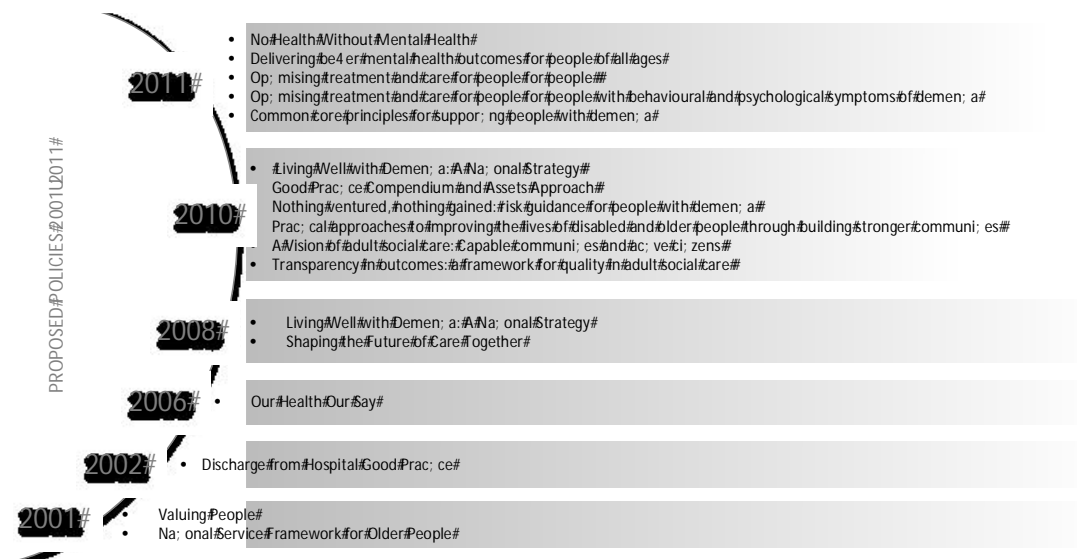


Figure 1: Integrated Dementia Care Policy Timeline

It can be seen from the timeline that there has been a steady increase in policies relating to integrated dementia care, highlighting its priority to the Government.

The first policy to have recorded impact was The National Service Framework for Older People published in 2001. This policy was dementia and integrated care specific; although the impacts recorded do relate to older people they are not specifically to people with dementia. Impacts include: decrease in "explicit" age discrimination through the accessibility to services to most older people, increase of older people stopping smoking and receiving flu jabs has increase, increase in the number of older people remaining in their own homes inclusion of older people in other organisations' activities (Commission for Healthcare Audit and Inspection, 2006).

The second policy related document to have recorded impact was Living Well with Dementia: A National Dementia Strategy (2009). This document was also dementia and integrated care specific, however the impact recorded was not on the person with dementia but instead on the methods of working of the organisations, with 90% of PCTs working with LAs to develop and/or deliver a joint dementia strategy (APPG 2011).

Having refreshed the 2009 National Dementia Strategy in September 2010 the Government set "Quality Standards" through NICE, to ensure high quality, cost-effective patient care. However the body that is to assess whether the guidelines are in fact being followed have not yet been developed (2011).

From the data within the conceptual framework, using mapping techniques, the different areas of integration could be identified and grouped according to similarity and dissimilarity criteria, to develop categories that could then form a taxonomy of integrated dementia care. The taxonomy was made of four elements: people, finance, control and infrastructure. Each element is required for integrated dementia care to occur successfully, therefore impact of integrated care could be measured according to the taxonomy.

The work of Kodner and Spreeuwenberg (2002) similarly identified categories within integrated care they included: Funding, Administrative, Organisational, Service delivery and Clinical. As did Hudson et al., (1997) who categorised the barriers to integrated health and social care specifically for older people with mental health into: Structural, Procedural, Financial, Professional, Status and legitimacy. Parallels between these two existing categorisations of integration within healthcare could be made with the data within the conceptual framework.

Table 1 provides a definition of each of these categories and illustrates the links between the categories identified by Hudson, et al., (1997), Kodner and Spreeuwenberg (2002) and the ICTPD. Only four categories were identified in the ICTPD instead of the five identified by the previous authors. The ICTPD's people category overlaps the two categories identified by (Hudson et al., 1997) "status and legitimacy" and "professional"; and the two corresponding categories identified by Kodner and Spreeuwenberg (2002) "Organisational" and "clinical" categories. The boundaries between these two categories were not definite and the definitions blurred

Table 1: Integrated Care Taxonomies and Definition

| Hudson | Kodner | ICTPD | Definition |
|-----------------------|------------------|----------------|--|
| Status and legitimacy | Organisational | People | Ways that individuals and professional groups work vertically and horizontally across the system to provide an integrated patient focused service. |
| Professional | Clinical | | |
| Structural | Service delivery | Infrastructure | Methods that are in place across the different agencies to deliver and promote integrated working (e.g. ICTPD systems, training) |
| Procedural | Administrative | Control | Top down control through strategies and ways of working specifically integrated ways. The way government and administrative functions are structured and devolved. |
| Financial | Funding | Finances | The funding mechanisms and financial resources for delivering care. Funding of care is condition related. |

The ICTPD can now be used to guide a number of other issues in the research, such as the choice of case study and the classification of the barriers and enablers to integrated care delivery to older people with dementia. It was also used to identify the areas that the impact studies looked into.

The impact study into The National Service Framework for Older People (2001) looked into the people and infrastructure categories. Whilst the second impact study on Living Well with Dementia: A National Dementia Strategy focused upon the

financial categories. It would be the author's recommendation for any impact study to be as comprehensive as possible it should look at the 4 categories within the ICTPD.

Discussion and Final Remarks

This research is part of on-going PhD research, focused on identifying the impact of integrate health and social care delivery on the wellbeing of people with dementia. Research in this area is very much needed as demographic changes towards an ageing population increasing the number of people living with dementia in the UK and other parts of the world.

The systematic review has been carried out with the objective of further understand care integration and the impact it has on people with dementia. From the review a number of issues have arisen:

- There is a lack of clarity regarding the term integrated care;
- Very little evidence exists on the impact of integrated care on dementia care;
- Integration within health and social care can fall into four key areas they are people, control, infrastructure and finance.
- Lack of follow up from policy into practice, integration is consistently promoted from the top, health and social care organisations are left to their own devices to put it into practice;
- The timeline generated show that policies relating to integrated dementia care have become more frequent in recent years, as shown in the time
- Government focus has only recently moved to dementia as illustrated by the timeline.
- Integration can be categorised into four key areas: People, control, infrastructure and finances.
- The conceptual framework corroborated the gap in impact studies of integrated care for people with dementia and therefore justified the need for research in this area.

Governmental policy and its relating document should act as an enabler of new of integrated care systems. However, as the literature suggests, there is a gap between policy and its practical implementation (Jarrett et al, 2009), which is further widened by a real confusion over the term integrated care and integration. Integrated care is further hindered by a number of barriers, which include: overly bureaucratic governance arrangements, limited resources, inadequate leadership, professional and institutional barriers and protracted decision-making processes (Williams and Sullivan, 2010).

Evidence does show, however, that the Government has not ignored the lack of success in delivering an integrated care system, but has taken action. This action has taken form in the introduction of new ways to support an integrated care system, for instance one of its most recent pledges to make "joined-up and coordinated health and

care the norm by 2018 – with projects in every part of the country by 2015” (DoH, 2013).

The Government aim to achieve the above, joined-up care by 2018, by establishing a consensus on the definition of “what people say good integrated care and support looks and feels like” (DoH, 2013), Finding a definition for this is something that has not been done before. They also hope to develop “pioneer” areas by September 2013 from which they can learn innovative and practical approaches to delivering integrated care as quickly as possible. Finally as there is little evidence around the impact of integrated care they have pledged to develop new methods to measure user’s experience of integrated care.

The fact that the Government is continuing to consider different ways to integrate health and social care implies: indicates that health and social care are still not integrated. In this regards, Kings’ Fund (an independent charitable organisation) suggest a different approach, which follows the example of successful local initiatives. It involves placing the end user at the centre of the system, a single system that acts as a whole to provide that end user with the service they require.

This paper has presented the impact of high-level integrated care, through looking at policy documents as well as a taxonomy for integrated dementia care. Future stages of the research include identification of barriers and enablers to integrated care and a case study to generate primary evidence into the impact of an integrated process on people with dementia (Yin, 1999). The impact search was restricted to documentation published up to 2012. For that reason, impact would have been harder to measure for some of the later documents; therefore a further review into impacts, where more time had passed since the publication of policy would be beneficial.

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